

Children with type 1-diabetes from ethnic minorities: vulnerable patients needing a tailored medical support (*)

Maurizio Vanelli, Antonina Marta Cangeli, Lavinia Fanciullo, Chiara Scarabello, Giorgia Monti, Dimitra Gkliati, Carla Mastrorilli, Brunella Iovane, Giovanni Chiari

Regional center for children and adolescents with diabetes, Children hospital, University hospital, Parma, Italy

Abstract. *Background and aim:* Newly diagnosed children with type 1 diabetes from ethnic minorities are a growing presence in outpatient pediatric clinics, and are reported as a group at risk of poor metabolic control. In the present study we investigated the barriers affecting chances of minority diabetic children to achieve the same metabolic targets of native peers with type 1 diabetes. *MaterialS and Methods:* The study investigated 35 children from ethnic minorities (group 1) admitted to the Children University Hospital of Parma, Italy, from 1st January 2000 to December 31st, 2011, and data concerning current age, gender, ethnicity, age at diabetes onset, HbA1c, DKA severity degree at diagnosis, insulin therapy, annual number of outpatient clinic visits, number of admissions for acute decompensation, and treatment cost. A short questionnaire on background, family situation, difficulties in diabetes monitoring, and outpatient clinic procedures completed the study. The results were compared with data collected from 30 matched native peers (group 2). *Results:* Mean HbA1c level at admittance was higher in Group 1 (11.8±1.0%) than in Group 2 (9.0±2.2%; p=0.000). The differences were confirmed when HbA1c mean cumulative values (8.6±2.1 vs 7.6±1.1; p=0.022) were calculated. Group 1 children at admission showed poorer metabolic conditions and longer stay at hospital (16±3 days) than Group 2 patients (8±2 days; p=0.000). The total costs for DKA treatment and family education resulted higher in Group 1 (+54%) than in Group 2 patients. Discontinuous capillary blood glucose monitoring and outpatient clinic visits missed were more frequent in Group 1 than in Group 2 patients. Thirteen patients in Group 1 needed a re-admittance to hospital because of a hypoglycemia (5 cases) or a hyperglycemia (8 cases). The same episodes were not recorded in Group 2 patients. Most of parents expressed the wish to be supported with educational material in their own language. *Conclusions:* Children with TDM belonging to an ethnic minority had poorer metabolic control compared with native patients. This results from several cultural, educational, economic deficiencies which influence their family life and probably reduced their chances to obtain a better control. (www.actabiomedica.it)

Key words: type 1 diabetes, children, ethnic minorities, immigrants

Introduction

Given the data from national department of statistic, Italy may be considered as a multicultural country (1). At this time, the minority people living in Italy amounts to 7.5% of the total number of residents. In

Emilia Romagna Region, where the present study was carried out, 21% of this migrant population is made up of children (1). This demographic phenomenon led to an expected rise in newly diagnosed diabetic children (T1DM) from ethnic minority population too (2).

Type 1 diabetes is a disease requiring a continuous family and patient collaboration in insulin injection, blood glucose monitoring, food intake and physical activity. This demanding engagement of migrant

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families and young people commonly conflicts with several barriers such as difficulties in understanding healthcare professional messages, in approaching the Italian healthcare system, in coping cultural, religious, educational and economic background with the requirements of a disease never known before.

This clash rises in general some barriers against good metabolic control in minority youth with T1DM (4, 5), also in a country like Italy where insulin, test material, access to hospital and outpatient clinics are free. In this scenario, the first step of investigation is analyzing the differences in diabetes at onset and in health outcomes in these two different groups. The knowledge of possible barriers could represent an useful tool for health care providers to plan the most suitable health measures.

This was the purpose of the present study which investigated children with T1DM belonging to an ethnic minority admitted to the Department of Pediatric of Parma University Hospital from 1st January 2000 to December 31st, 2011. The study started from 1st January 2000 because no minority child with T1DM was found in the local registry before this date.

Materials and methods

Two groups of patients with T1DM were compared in this study. The first one concerned children belonging to an ethnic minority with T1DM either newly diagnosed in our Department or previously diagnosed in their own native country (Group 1). These children were born from migrant parents coming from a country outside the European Community and resident in Italy. The second group of patients regarded some matched native children who developed T1DM in the same study period selected according to randomized criteria (Group 2). The patients of both groups attended the same outpatient clinics of the Regional Center for children with T1DM of the Children University Hospital of Parma, Italy.

The medical charts of both Groups of patients were reviewed from 1st January 2000 to December 31st, 2011, and the following relevant data were collected: current age, gender, ethnicity, age at diabetes onset, glycated hemoglobin (HbA1c), diabetes ketoacidosis

(DKA) severity degree at diagnosis, insulin therapy, diabetes duration, annual number of out patient clinic visits, number of severe hypoglycemia episodes (unconsciousness and/or seizures), number of admissions for acute decompensation, treatment cost.

Regardless of ethnicity, the enrolled patients were managed according to the same protocol for DKA treatment, diabetes education, ambulatory care and monitoring of metabolic control procedure (5, 6). The burden of this process was sustained by the same physicians and nurses team. When needing, Italian booklets translated in English or Arabic were used to help ethnic minority parents to better understand the diabetes management rules.

At the time of discharge from hospital parents and patients received consistent and repeated educational advices for hypoglycemia and DKA prevention. A meeting with a dietician and a social worker was organized. Sticks for capillary blood glucose determination, urine glucose assay, insulin and syringes were free distributed. An emergency telephone support 24 hours a day was provided too (7). During the first 4 months from diagnosis the patients were reviewed in outpatient clinics one time a week, and afterwards three to four times a year.

Immediately before starting the study, parents of ethnic minority children were invited to answer a short questionnaire concerning background, situation of the family, satisfaction about educational tools for diabetes management, difficulties in diabetes monitoring at home and at school, and follow up at outpatient clinic. The questionnaire was given by interpreters who were stressed to translate and not interpret the answers of the parents. Socioeconomic families' status was evaluated according Schizzerotto's model (8).

Glycated hemoglobin was assayed at each quarterly clinical appointment by DCA-2000 system (.....). Medical costs for all treatment groups were estimated from current (May 2011) Parma's University Hospital inpatient price lists.

The collected data was analyzed using the statistical package SPSS for Windows and expressed as mean \pm SD. The numerical differences were calculated with the Student t-test. To study the differences between the proportions χ^2 test was used. The differences were considered as significant if $p < 0.05$.

Results

From 1st January 2000 to December 31st 2011, 155 children were admitted to the Children University Hospital of Parma, Italy, because of a T1DM. Thirty-five children belonged to an ethnic minority (22.6%) (Group 1). Thirty matched native children among those who developed T1DM in the same period of the study were enrolled as control group (19,3%) (Group 2). Patients characteristics are summarized in Table 1.

Twenty families in Group 1 were from Northern Africa (Algeria, Morocco and Tunisia), 6 from Eastern Europe (Moldova and Albania), 4 from India, 3 from the Middle East (2 from Iran and 1 from Pakistan), 2 from Chile. In twenty-seven Group 1 patients (77%) T1DM was diagnosed in Italy. In the other 8 patients the diagnosis was done in their own native country. At the time of investigation 77% (n=27) of the fathers and 36% (n=12) of the mothers in Group 1 were working. Three fathers were single. No one parent was aware that diabetes could appear in children too.

All parents of Group 1 had a school and professional education degree lower than the parents of Group 2 patients. Great differences were found in socioeconomic status between native and ethnic minority families. While in native families middle class professions were equally distributed, in minority families low social levels were prevalent (Fig. 1).

T1DM was diagnosed at the same age in both Group 1 and 2 patients (7.3 ± 3.1 vs 7.0 ± 3.5 years, $p=0.935$). Latency between first collected symptom

Table 1. Patient characteristics

Patients	Group 1	Group 2
n.	35	30
Gender	15 F; 20 M	12 F; 18 M
Age (years)	9.4 ± 4.4	9.5 ± 4.5
Age at T1DM onset (years)	7.0 ± 3.7	7.1 ± 3.9
HbA1c (%)	$11,84 \pm 1,02$	$9 \pm 2,22^*$
Blood Glucose (md/dl)	$380,4 \pm 10,2$	$295,7 \pm 8,1^*$
HCO ₃ ⁻ (mEq/l)	$12,7 \pm 5,0$	$16,7 \pm 4,9^{**}$
pH	$7,17 \pm 0,1$	$7,26 \pm 0,1^*$
Latency before diagnosis (n. days)	11.5 ± 2.8	$6.6 \pm 3.2^*$

Data are mean \pm SDS. * $p=0.000$; ** $p=0.003$

reliable to a permanent hyperglycemia and T1DM clinical diagnosis was longer in Group 1 (11.5 ± 2.8 days) than in Group 2 patients (6.6 ± 3.2 days; $t=5.913$; $p=0.000$). Group 1 children diagnosed in Italy were at admission in poorer metabolic conditions (Tab. 1) and stayed at hospital longer (16 ± 3 days) than those of Group 2 patients (8 ± 2 days; $t=12.153$, $p=0.000$).

The hours devoted by healthcare givers to self-control education before discharge were more numerous in Group 1 than in Group 2 patients (10.5 ± 4.5 vs. 6 ± 1.5 hours; $t=3.244$; $p=0.003$). In 48% of Group 1 children healthcare professionals needed an interpreter to communicate with parents. The total costs for DKA treatment and family education resulted higher in Group 1 (+54%) than in Group 2 patients.

Insulin regimen in Group 1 children was tailored to the dexterity of their parents: 14/27 patients were treated with 3 daily biphasic insulin injections; 7/27

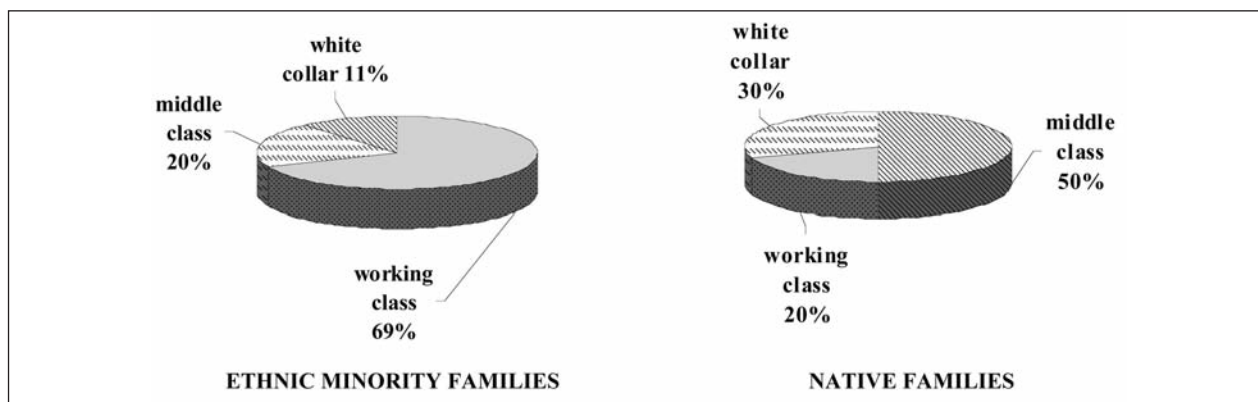


Figure 1. Socio economic status in ethnic minority and native families

with twice daily long-acting insulin injections; and 6/27 with basal-bolus regimen. Group 2 children were treated with the same basal-bolus regimen. Group 1 and 2 patients did not differ in mean insulin dose (1.0 ± 0.2 vs 0.8 ± 0.3 U/kg), at the time of investigation.

Mean HbA1c level at admittance were higher in Group 1 ($11.8 \pm 1.0\%$) than in Group 2 ($9.0 \pm 2.2\%$; $t=6.765$; $p=0.000$). The differences between groups were confirmed when HbA1c mean values over 12 years study were calculated (8.6 ± 2.1 vs 7.6 ± 1.1 ; $t=2.245$; $p=0.022$). At the time of study beginning mean HbA1c value in Group 1 ($8.2 \pm 1.9\%$) was always higher than in Group 2 patients ($7.2 \pm 0.8\%$; $t=2.684$; $p=0.009$).

After discharge, 13 patients in Group 1 needed a re-admittance to hospital because of an acute decompensation reliable to a hypoglycemia (5 cases) or a hyperglycemia (8 cases); the stay at hospital ranged from 3 to 12 days. The same episodes were not recorded in Group 2 patients.

Discontinuous capillary blood glucose monitoring at home resulted more frequent in Group 1 (28%) than in Group 2 patients (12%, $p<0.005$). Outpatient clinic visits were missed more frequently by ethnic minority (32%) than native patients (6%, $p<0.001$).

The involvement of social worker service was more frequently required for patients in Group 1 (72%) than for those in Group 2 (12%; $p<0.0001$) and were focused on school (65%), national healthcare system (11%) and employers (24%) problems. Interventions at school concerned diet plan (38%), requirement to know more about diabetes, school performance (35%) and physical activity (27%).

Forty-five percent of parents of Group 1 patients asked a specific meeting with a dietician in order to prepare a food plan tailored to the family traditions. Eighty-five percent of ethnic minorities parents ($n=30$) reported to be very satisfied with the provided diabetes education program; 5 parents denied to comment. Most of parents expressed the wish to be supported with educational material in their own language. Arabic parents had appreciated to have an educational booklet in their own language. No parent reported to be in contact with other native families with a child with T1DM. This is a great desire shared by all of ethnic minorities parents.

The present study shows some limitations. At first, the number of participants is small, but it is representative of a local experience. The Authors are convinced that in the ethnic minority field local investigations more than larger studies are useful to find effective solutions to barriers for diabetes management in this vulnerable population. Secondly, the questionnaire has been administered by interpreters, and this procedure could result in misunderstandings. These operators were professional interpreters and were taught to translate and not interpret families queries and replies. The risk of mistakes may be reasonably considered low.

Discussion

Health care for children with T1DM belonging to an ethnic minority is a recent acquisition in the Italian diabetes centers (3). Before 2000 no minority child with T1D was admitted to our regional Center. In about 10 years, 35 minority children with T1DM were treated, with an annual rate of 3.2 patients per year. Most of these minority children were newly diagnosed in Italy, but in a few number of patients the diagnosis was made in their own native country.

Researchers have demonstrated that these patients show higher risk for poor metabolic control than native peers (4, 9, 10). There is a general agreement that recurrent acute decompensations and chronic hyperglycemia increase health complications (DCCT), and reduce quality of life (11, 12). It is thus imperative that caregivers know the factors which affect the ethnic minorities chances to achieve the same treatment and to have the same health standard support of their native peers with T1DM. In this perspective, it is useful that, in addition to national studies which globally analyze the immigrants phenomenon, local investigations have to be encouraged in order to promote a capillary action adapted to the local resources and to the ethnic minorities behaviors.

About metabolic control, the data collected for this study confirm that minority children have at diagnosis a more serious metabolic derangement than their native peers. This may be due to the fact that most of their parents did not know that children can have dia-

betes too, and therefore they were unable to recognize the warning symptoms of a diabetes at onset. An unusual bed wetting in a child usually dry is in general accepted as an early sign of a progressive hyperglycemia (13). When this is well considered and punctually investigated, the diabetes may be early diagnosed and DKA appearance may be prevented (14). In the present investigation no one ethnic minority parent recognized this sign, and consequently the latency before diabetes diagnosis in their children resulted longer than in native group, where 45% of parents perceived these unusual bed wetting episodes as an anomalous situation to be reported to the pediatrician.

This gap in information may be filled reproducing the campaign against DKA successfully promoted in Parma in native people in the Nineties (13). The same leaflets, translated in the most common ethnic minority languages, could be spread in pediatricians' offices, pharmacies, pediatrics emergency departments, cult places and pediatrics outpatient clinics attended by ethnic minorities. The essential thing is to put in circulation this elementary but effective message having long-dated results too (15)

Data herein collected confirm, in agreement with other Authors, that low HbA1c values continue to be a difficult end-point for children from ethnic minorities (3, 4, 16). Several barriers are involved in the missing of this target. Some of them have been pointed up in the current investigation too.

Knowledge of diabetes is generally limited in minority families (3). All parents herein investigated were entirely in the dark about diabetes, and this lack of information could be partially ascribed to the fact they came from countries with low incidence of T1DM or where the disease was undiagnosed. This conditions caused several troubles to professional caregivers in communicating diagnosis, treatment rules, education procedures, follow up planning, and it needed the intervention of interpreters with a consequent rise in the costs. The use of professionals operators is generally recommended by different Authors (9, 17), but it is clear that the indirect communication results less effective compared to a native population.

In our experience, the translation in English, French and Arabic of current Italian booklets for diabetes self-control education met a widespread success

to improve families knowledge. Thanks to these resources, each minority family has received individual education in diabetes as well as the native families, but at a high price of numerous hours of work.

Insufficient Italian knowledge represented for minority families a further barrier in communicating with other families and in accessing to national health care system and schools. These difficulties was partially overcome by the support of a home-care-like organization that our group had well experimented few years ago sending a nursing or a social worker to home and schools (18). To lower the marginalized social position of which all minority families complained, parents association of diabetic children in Parma promoted specific families-guide. Socialization was an urgent request by the disadvantaged families included in this study.

A part the related microvascular complications, an insufficient blood glucose control has been associated with a poorer quality of life too, as the Hvidovre study group and other Authors have previously demonstrated (11, 12). The limited cultural background and the discontinuous stay at home of parents found in this study could be considered as a barrier to perform in minority children an advanced insulin treatment such as the basal bolus regimen. This barrier could be pulled down with the families-guide or with the nurses of the home care service (18).

Less knowledge of diabetes is in general linked to a little educational and cultural background (3). All minority parents in this study had a school and professional education degree lower than the parents of native patients. This condition required an up-to-date of outpatient clinics planning. The minority patients could be seen in restricted days with the participation of teaching nurse, social worker, dietitian and an interpreter if needing as well as the outpatient visits which have to be planned to last longer than usually.

In addition to these facilities, we agree the Authors who sustain that in working with ethnic minorities professional caregivers should be trained in religion, cultural, educational patterns of the families, in order to know the new perception of health and disease (3).

In conclusion, children with T1DM belonging to an ethnic minority show poorer metabolic control

compared with native patients. This results from several cultural, educational, economic deficiencies which deeply influence their family life and probably reduce their chances to obtain a better control. Limited Italian knowledge of parents represents an important barrier in communicating with healthcare professionals and in understanding procedures for diabetes management at home. Face to this background, caregivers have to be encouraged to provide tailored support for both patients and families. Outpatient clinic visits have to be integrated with a home-care service-like which involves nurse teaching, social worker, interpreter and dietitian. Translation in English, French and Arabic of Italian booklets focused on teaching diabetes self-management could be an effective tool to involve and improve families knowledge and collaboration. An excellent contribution to remove the marginalized social position of minority families seems to be the promotion of native families-guide.

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Correspondence: Maurizio Vanelli, MD

Regional center for children and adolescents with diabetes

Children hospital, University hospital,

v.le A. Gramsci, 14

43100 Parma, Italy

E-mail: maurizio.vanelli@unipr.it